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ABSTRACT

This theme issue focuses on the relationship of fathers and their children with disabilities. It reports a study of 86 Kansas fathers of children (ages 5 to 8) with and without disabilities. The study was conducted in order to identify more options for fathers wishing to increase their involvement with their children. The study sent surveys of parenting competence and three measures of time spent in various activities to fathers randomly selected from Kansas school districts. About half the 86 fathers included in the study had children with mental retardation. The study's main finding was that having a child with a disability did not seem to alter a father's concept of his fathering competence, nor the amount of time he spent caring for his child. The study resulted in the following recommendations for service providers: (1) learn from fathers their priorities for their children and suggest activities that respond to those priorities; (2) work with fathers to talk more with their children; and (3) tap the problem-solving orientation of fathers, such as discussing ways to adapt toys. The newsletter also provides contact information and a brief description of seven resources for fathers, a vignette describing the coping strategies of one father whose daughter was severely brain damaged as a result of spinal meningitis, a discussion of how fathers may feel left out when dealing with service providers, and suggestions for involving fathers more with their special needs children. (DB)

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THE UNIVERSITY OF KANSAS
Beach Center on Families and Disability

Families and Disability Newsletter

Volume 6, Number 3 Winter 1995

Dads and Disability

A few years ago, Dr. Vicki Turbiville was attending a class on collaboration between families and service providers. The sole male there said he would rather talk with mothers about their children than fathers.

Turbiville remembered thinking at the time that if male teachers don't want to talk with fathers, then fathers must really be out of the information loop. This thought set in motion a line of research centering around the priorities and preferences of fathers with children who have disabilities and how service providers respond to fathers.

Throughout the studies, Turbiville has been advised by a number of fathers who have children with disabilities. "I'm obviously not a father," Turbiville said. "So to be sure that what we do and what we learn is accurate and appropriate, I need feedback from those who are fathers."

Routinely talking with fathers around the country, Turbiville has developed questions to be answered by her research, conducted studies, and reported the findings.

Research findings

In her study, Turbiville found that fathers of children with and without disabilities spend about the same amount of time with their children. While fathers whose children have disabilities reported spending a bit more time doing child care, Turbiville said that the difference in the time they spent and time spent by fathers whose children did not have disabilities was statistically insignificant.

"I was glad to find that the results confirmed my hypothesis," Turbiville said. "There have been suggestions that fathers of children who have disabilities are not as involved with their children. My study found that not to be the case.

"The big piece was that both groups of fathers perceive themselves as equally good parents. They feel equally competent."

Eighty-six fathers in Kansas provided the study information. About half of these fathers had children who have mental retardation.

Other findings included:

- Fathers reported that they watch a lot of television with their children.
- Fathers of children who had a disability reported spending more time at home than did fathers whose children did not have disabilities.
- Fathers of children who had disabilities were more inclined to hold their children and engage in nonverbal interaction (e.g., tickling) than were fathers of children who did not have a disability.

Turbiville's Fathers Study

Who: 84 Kansas fathers of children 5-8 years of age with and without disabilities
Why: Identify more options for fathers' participation with their children based on their current activities
When: 1994
How: Parenting competence surveys and three measures of time spent in various activities were mailed to fathers randomly selected from Kansas school districts
Where: Beach Center on Families and Disability
BOTTOM LINE: This study examined how fathers of children with and without disabilities spend time with their children and how they see themselves as fathers. Having a child with a disability did not seem to alter a father's concept of his fathering, nor the amount of time he spent caring for his child.

One Family's Story.....3
Dads Feel Left Out.....4
Fact Sheet.....5
Beach Updates.....7
Check It Out.....8

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Research implications

Based on the study, Turbiville suggests that service providers:

- Learn from fathers their priorities for their children and suggest activities that respond to those priorities
- Work with fathers to talk more with their children.
- Tap the problem-solving orientation of fathers, such as discussing ways to adapt toys.

Current research

Turbiville and Beach research assistants Terese Maier and Gardner Umbarger are now identifying strategies that programs serving children between birth and age 8 are using to involve fathers.

Said Umbarger, a former special education teacher, "I like working on this project, being a father myself. I appreciate the difficulties fathers face dealing with service providers and general perceptions about male competency to deal with children."

Currently, information is being sought from programs in early intervention, preschool special education, Head Start, and community day care regarding approaches used to include fathers in programs for their children; information from fathers on how they feel about those approaches; and how they would like to be included.

If you would like to participate in the project, please contact Dr. Vicki Turbiville at (913) 864-7607 or Vicki @dole.lsi.ukans.edu.

Recommended Resources

National Fathers' Network. Headed by James May, the Network advocates for fathers and families of children with special needs and sets up father support programs. At program meetings, fathers have social time, a sharing discussion, father-child activities, and speakers on identified interest topics. Its *National Fathers' Network Newsletter* features articles of general interest to men and families of children with special needs. For more information, contact: National Fathers' Network, The Kindering Center, 16120 NE Eighth Street, Bellevue, WA 98008 (206-747-4004 or 206-282-1069).

Fathers' Voices. This regular column in *Exceptional Parent* magazine (800-247-808) focuses on fathers who have children with disabilities. From the March 1995 issue, Louie Mauro writes of his son: *"At 12 and a half months, he began saying his first words. At 13 months, he was struck by a drunk driver. The development books were thrown out. Alex's severe brain injury destroyed most of his former functioning, leaving only unanswered questions. . . Believing that 'normal' development was still an appropriate goal, we embarked on a plan to bring our child back."*

Dadvocat. This bulletin board on the Internet was hatched at the 1994 Parent to Parent Conference in North Carolina. To subscribe: DADVOCAT@UKCC.uky.ed

Fathers of Children With Special Needs: New Horizons. J. May. (1991). (Bethesda, MD: Association for the Care of Children's Health). Offers fathers' views of living with their child's disability and has several tips for service providers.

Uncommon Fathers: Reflections on Raising a Child With a Disability. Edited by Donald Meyer. (1995). Woodbine House. $14.95 + $4 shipping. 224 pages. (1-800-843-7323). The first book written for fathers by fathers of children with developmental disabilities. In these candid essays, fathers convey their pride, rage, humor, and deep love for their children with special needs.

What Research Says About Fathers, Their Children, and Disability. This easy-to-read booklet presents relevant research findings from the last 30 years on fathering issues relating to a child with a disability. $2.00.

Fathers and Family-Centered Early Intervention. V. P. Turbiville, A. P. Turnbull, & H. R Turnbull, III. (1995). *Infants and Young Children,* 7(4), 12-19. This research article reviews the influence of a fathers' positive relationships with their children and suggests approaches for service providers to facilitate father involvement with early intervention services.

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Editor: Cindy Higgins

One Dad Who Makes a Difference

Bob Dale, Portageville, Missouri, is an active advocate for children with disabilities. The following are excerpts from the chapter "Creating Answers" in "Uncommon Fathers: Reflection on Raising a Child With a Disability." (Woodbine House, see page 2)

Smile of beauty. In February of 1990 my daughter Jessica, was a happy, healthy seven-month-old, pulling up and walking along the edge of the sofa, smiling a smile so bright and beautiful that angels were envious.

Today Jessica lies virtually motionless on her back--deaf, blind, and paralyzed, but still smiling that angelic smile and displaying the nature of the unimpaired beauty that was born to us. [Jessica had spinal meningitis.]

A good cry. Most fathers are told to do the same thing I was:

Be strong for your family.

Sometimes I don't feel very strong. Someitmes I'm tired and want all of it to go away.

Sometimes I cry. I let my two boys know they can cry, too.

Sometimes we cry together.

Taking a break. How do you take care of Jessica, and Zachary, and Devon and Robbie and yourself without blowing a gasket?

Over the years we have devised an answer: We escape!

I arrange for help with Jessica from whatever resources are available and plan a time to do something with the rest of the family. I think the operative word here is plan.

Appreciation of today. How do I characterize my relationship with Jessica?

I don't know.

You need to realize that Jesse is not expected to live much past the age of twelve or thirteen, so every moment with her is a precious gift; a point in time to be savored.

Every smile is a prayer answered. Every time I stroke her cheek I feel a sense of wonder and appreciation that she is here, with me now.

Life directions. Because of Jessica, I have increased my awareness of people with disabilities.

I have become educated in many areas of policy and law, and I have attended over fifty I.E.P. meetings, other than hers, to help other kids get the most out of their education.

Because of her I have met hundreds of parents, and talked at length with them about the challenges they face raising their child with special needs.

I have lobbied our state legislature for Jessica, and together with hundreds of other parents, helped to effect positive change in the state of Missouri.

Because of Jessica I have helped to raise the level of awareness of to the part of state officials and educators. All because of a little four-year-old girl.

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Dads Feel Left Out

Fathers often report that they feel like second-class citizens when dealing with service providers. "One time I was trying to say that I felt like less than a parent when I was dealing with service providers," said one dad. "But the words ran together and I ended up saying 'I felt less apparent to service providers,' and that was true, too."

According to James May, Project Director, National Fathers' Network, Bellevue, WA, their reasons for this are many.

Service delivery schedules. For one, professional services tend to be offered during the day when many fathers are at their place of employment. This typically results in mothers, even employed mothers, becoming the "experts" on the child. This situation can leave fathers out of the information loop.

Gender differences. When a father does meet with service providers or attend a program for couples, generally he will be surrounded by women, which may make him uncomfortable. Discomfort may arise from the providers' way of sharing information, or it could be that fathers have needs that female service providers aren't responding to adequately.

Said one dad, "A lot of the providers seem to be women. When they run into us, well, we have a different set of feelings. We have frustrations that they may not be familiar with. Sometimes they say things we don't appreciate."

Self-expression difficulties. Wrote another dad on the Internet, "It seems to me we guys are less likely to share our feelings, do it rather badly when we do, and are more likely to be blasted. When we talk feeling like the world is on our shoulders--this is not a discount on moms who feel the same way--it is a feeling, not a rational statement of fact. I am told that many fathers become overwhelmed and bail out of marriages when handicapped children enter the picture. Those of us who are working to stick it out need as much nurturing (not more) as our spouses."

The difficulty in self-expression this father refers to makes it tough for service providers to communicate with fathers. Service providers who encourage fathers to discuss their feelings may find fathers unresponsive to this approach preferred by mothers.

Child interaction differences. Another fact that service providers need to recognize is that fathers differ in expression from mothers. They also interact differently with their child, which may influence a provider's suggested activities and recommendations.

For instance, one father said he felt most useful to his 7-year-old son with multiple disabilities when he made practical devices (e.g., drawing board to hold paper and markers) to make his son's life easier.

Another father of a young daughter with rare chromosome deletion said that his wife was good at working with their daughter, but he was best at playing. His daughter liked him to get down on his hands and knees and chase her.

Or when she is in the bathtub and calls "a-dee-dee-dee," her word for "Daddy," he replies,"I hear you in there,"which makes her laugh. This play benefits the child as it encourages exploration as well as increasing the child's self-esteem.

Making adaptive devices, play, and verbal interaction are ways that fathers prefer to spend time with their children. If services are tailored to fit these preferences, then fathers will be more likely to get involved.

Inadvertent discouragement. And, if fathers do get involved, service providers can capitalize on that interest, rather than discourage it un- intentionally. Imagine what this St. Louis father felt when he was called a "father hen" by service providers, because he wanted to participate in his child's Individualized Education Program (IEP) development.

Not only was it implied that he was over protective, but use of "mother hen" implied that he was playing an inappropriate role.

His experience was similar to that of Bob Dale, who said (see *One Dad Who Makes a Difference, p.3*):

"Once, after answering a social worker's questions, I was thanked for my cooperation and informed that the worker would check my answers with my wife for accuracy.

"I found this very curious, especially since the questions dealt with my work record and employment history. It would be easy to step aside and let my wife take charge of these activities. After all, stepping aside was the message sent loudly and clearly to me from many places. But my wife couldn't deal with this trauma alone.

"It took two of us to handle all that was happening; service providers would just have to get to know me and learn to accept, if not like, the fact that I was involved with my daughter's life."

Beach Center
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How To:

Involve Fathers More With Their Children With Special Needs

Mothers are typically viewed as overseeing their children's education and development, while fathers are thought to be less involved. There are good reasons for this often true perception. However, better reasons exist to change it and to use the commonly untapped resource of fathers when working with a family that has a child with a disability.

Unfortunately, there isn't much research on fathers and even less on fathers who have children with disabilities to guide the way.

What is known is that fathers of children with disabilities think of themselves as pretty much the same as fathers of children without disabilities. They both spend about the same amount of time caring for their children and generally take on the role of playmate rather than care giver.

As strong influences on the child and family unit, fathers affect their children's cognitive, personal-social, and sex-role identification development.

Children who have positive relationships with their fathers tend to have higher achievement, motivation, cognitive competence, and better social skills.

Fathers who view their children with disabilities positively also encourage mothers in their child care activities.

Factors that influence a father's relationship with his child include the parents' employment, their personal and cultural characteristics, and the child's traits (including temperament and gender).

Service providers should value the participation of fathers and other male family members. They should also recognize that every male in a child's life has strengths and these strengths play a major role in family functioning.

Therefore, personally invite fathers and male family members to take part in all aspects of service provision. Focus first on providing information to fathers, then work on relationship building.

The following research knowledge can be used to encourage father-child relationships and increase inclusion of fathers and other male family members in programs.

1. While fathers of children without disabilities spend more time with their children out of the home in such activities as going to church, cleaning the garage, or grocery shopping together, fathers with children who have disabilities tend to interact with their children in the home. Often, this is because a father finds routine activities less disruptive to the child and family. And the child's disability might make leaving the home difficult. The father also may be uncomfortable with public scrutiny of his highly visible child. Therefore, some fathers may be more comfortable with activities that they can do at home within the home routine.

2. Fathers tend not to follow activities suggested by educators. When recommending activities, find out the father's particular present activities and preferences. Build on these.

3. Television watching, fathers report, is how they spend a great deal of time with their child-

ren. Collaborate with fathers to identify strategies to increase child interaction during television watching (e.g., lap sitting, questions about program content).

4. Fathers like problem solving. Focus on activities for fathers that incorporate problem solving with their children, such as toy or transportation adaptation.

5. Fathers' play differs from mothers' play, which typically is more educational in nature. Fathers' play (often in shorter sessions) tends to be more physical, spontaneous, and unpredictable. If planning father-oriented games and activities, take note of the play difference.

6. Fathers tend to engage in fewer verbal activities with their children than do mothers. This can be exacerbated if their child has a disability because the father is rarely taught how to communicate with his child who has a disability. Not surprisingly, fathers report that they view the development of communication skills with their children as a high priority. This may be particularly true for fathers who have children with disabilities. Fathers suggest that they need information on interpreting non-verbal cues of their infants and toddlers.

Service providers should make sure that fathers have the opportunity to be included in the family-centered services provided to children with disabilities and their families. As with all family-centered practices, the mother and father can best decide how to include the father.

If you would like to know more about the research on fathers who have a child with a disability, contact the Beach Center on Families and Disability at 3111 Haworth, University of Kansas, Lawrence, KS 66045 (913-864-7600).

Other Beach Center "How To" fact sheets that you can order for $.50 each (price includes postage) are:

Get a Family-Friendly IFSP

Tell People What You Want

Start Your Own Parent to Parent Support Program

Better Cope With a Family Member's Disability

Recognize and Acknowledge Family Strengths

Learn About Laws That Impact Your Family's Life

Reduce Problem Behavior for Children Who Have Developmental Disabilities

Encourage Desirable Behavior in Children With Developmental Disabilities

Get Educational Services for Your Child Who Needs Technological Assistance

Obtain Quality, In-Home Nursing for Your Child Who Needs Technical Assistance

Better Your Student's (Requiring Technological Assistance) School Day

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Beach Center Updates

PBS training teams. Mike Ruef and Martha Blue-Banning, Beach Center, have completed their training on the Kansas 12-member positive behavior support training team. During the next four months, they will conduct training in various Kansas locations. Kansas joins 20 other state training teams across the United States in providing trainers experienced in dealing with challenging behavior. The training teams are a result of a grant project spearheaded by the Research and Training Center on Positive Behavioral Support headquartered at the University of Oregon. For further information, contact Mike at (913) 864-7603.

Lorenzo Awards. The Beach Center and the Inter-American Children's Institute presented the 1995 Eloisa de Lorenzo Awards in the category of Research in Social Sciences June 29 in Montevideo, Uruguay. Awardees included: Dr. Ingeburg Fuhrman, Centro de Estudios y Terapia Sistémica, Chile, "How to Reduce Harm in Families Who Have Disability; Dra. Julieta Zacarías Ponce, Centro de Adiestramiento Personal y Social, México, "Example of Independent Living Model"; Lic. Roberto Madriz, Fundación para la Cooperacion Internacional de Organizaciones Suecas de Discapacitados, Nicaragua, "People With Disability in Nicaragua"; and Fundación General Ecuatoriana, Ecuador, "Taking Care of Children With Mental Retardation."

ADA roundtable. Rud Turnbull, Beach Co-Director, recently participated in a ADA roundtable discussion convened for the President in Washington, D. C. Attorney General. Janet Reno, Treasury Secretary Robert Rubin, and assorted congressmen joined the discussion. After hearing President Clinton say, "There shall not be a life wasted in America," Turnbull, during his presentation, beseeched the president to maintain federal financing of local special education programs and block Republican efforts to slash welfare programs. "By God, we need you out front here!" Turnbull said to Clinton. "And, by God, if you lead, we'll be behind you all the way!"

P2P activities. Betsy Santelli and Sara Squires, Beach Center, met with their participatory action research team led by Dr. George Singer, University of California-Santa Barbara, to share preliminary results on the effectiveness of Parent to Parent programs. They are also beginning to work with the program planning team for the International Parent to Parent conference to be held March 29-April 1, 1996 in Albuquerque.

Medical technology. The Beach Center is conducting a study of the transition experiences of adolescents ages 14-21 who use medical technology (ventilator, gastrostomy, and dialysis). Beach researchers hope to develop better services to overcome existing barriers and to make recommendations for policy change. If you or someone you know would be willing to participate in this study, please call Rebecca Moberly, Gardner Umbarger, or Mary Morningstar at (913) 864-7602. Parents or proxies can be used if there is a condition that makes communication difficult.

If you would like more information about *The Beach Center on Families and Disability*, please send us this form.

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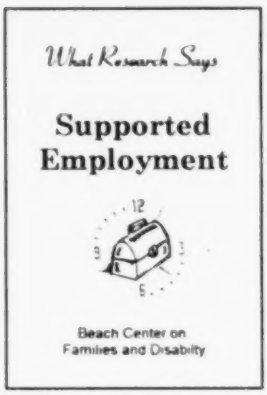
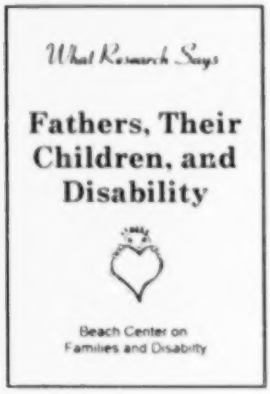
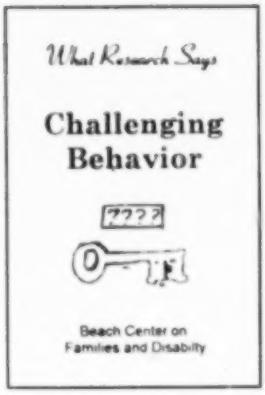
The Beach Center is introducing a new line of products--our family-friendly **What Research Says** series. These attractive booklets present research findings in an easy-to-read format. (We've thrown out the jargon and those sentences that go on and on. . . .) Each booklet summarizes relevant research and results from a Beach study. (For more detailed research information, see our literature reviews.) Expect to see more of these $2.00 booklets in the future.







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